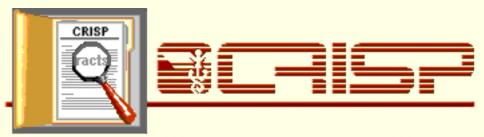
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Abstract

Grant Number: 5F31NR007454-02

PI Name: VOIGTMAN, JANET L.

PI Title:

Project Title: PERCEPTION OF PAIN IN SICKLE CELL DISEASE

Abstract: The purpose of this study is to clarify perceptions about, and effects and consequences of sickle cell anemia and associated pain in young sufferers, their families and communities in Saudi Arabia. Saudi Arabia's Eastern Province is the region exhibiting the highest incidence of sickle cell disease and was chosen as the study site. Research aims include description of: a) the cultural context in which the response to sickle cell disease and pain develops, b) affected children's perceptions of sickle cell disease and pain effects on their lives, and c) perceptions of family members of affected children with sickle cell disease and pain about disease and pain effects on the lives of affected relatives and families. A community view of sickle cell disease and pain is sought to provide a generic context. The perceptions of children with the disease and resultant pain will be assessed. The perspective of family caretakers assisting the child is also viewed as contributing to a richer portrait of the phenomena. An ethnographic methods approach is visualized with community members, affected children under the age of 14 years, and family caretakers providing data via participant-observation methods and interviews. Community member data will be obtained via informal interviews and participant-observation methods in venues such as hospitals, social events, and in other settings as available. Affected children and caretakers will be interviewed and audiotaped with data transcribed into Arabic and English for analysis. The product of data analysis will consist of categories and themes describing the cultural context of pain and sickle cell disease from individual, family and community bases.

Thesaurus Terms:

Arab, Arab country, pain threshold, sickle cell anemia, social perception

age difference, caregiver, developmental psychology, gender difference, religion adolescence (12-18), adult human (19+), behavioral /social science research tag, child (0-11), clinical research, human subject

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